

ARE WE LEAVING CHILDREN WITH CHRONIC ILLNESS BEHIND?

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ABSTRACT

Novel treatments are improving the prognosis for many illnesses, making it possible to survive diseases that were once considered fatal. With these advancements comes great responsibility to ensure quality of life for those living with chronic illness. Educators are among the group of professionals accountable for ensuring quality of life experiences for students living with chronic conditions. Unfortunately, typical educational systems and policies are not designed to lend support to students battling chronic illness. With limited resources to draw from, well-intended teachers and administrators respond to acute health episodes with impromptu plans, inadvertently creating educational barriers, eliminating the possibility of an equitable educational experience for students with an illness. Looking through the lens of these students, violations of best practice in education are plentiful. Analyzing existing research and laws to understand the path to success achieved for other vulnerable populations will likely guide future research initiatives that may lead to the solution so desperately needed for these children.

ARE WE LEAVING CHILDREN WITH CHRONIC ILLNESS BEHIND?

The advancement of medical research is sustaining life in ways that were not possible years ago. Novel treatments are improving the prognosis for many illnesses, making it possible to survive diseases that were once considered fatal.

68 PHYSICAL DISABILITIES: EDUCATION AND RELATED SERVICES

Thies (1999) captures the essence of this phenomenon with respect to one of the most feared illnesses: "Cancer has joined the ranks of chronic illness" (p.393). Five year survival estimates for childhood cancer survivors have increased from 59% in 1975 to 80% in 2002 (Surveillance, Epidemiology, and End Results[SEER] Program, 2010). Cutting edge technological advancements in pediatric medicine have allowed for reclassification of diseases once considered fatal or terminal to be categorized as chronic illnesses (Sexson & Madan-Swain, 1993).

While the aforementioned improvements are exciting, a paradox emerges, shining light on the responsibility to examine the quality of life of those living with a chronic illness. According to the National Institutes of Health 2006/2007 biennial director's report, the incidence of chronic illness is increasing at a rapid rate worldwide and the burden to care for these individuals is substantial. Issues of quality of life versus quantity of life are ever present as an awareness of the responsibility to consider quality of life in the treatment decision-making process is becoming common practice and appropriately involves the individuals with chronic conditions (Larsen, 2006). Unfortunately, literature investigating quality of life for these individuals as it pertains to education is limited and outdated.

Educators are among the group of professionals accountable for ensuring quality of life experiences for students living with chronic illness, yet typical educational systems and policies are not designed to lend support to students battling chronic illness:

Schools face challenges incorporating children with different illnesses into the classroom. [...] Most children spend nearly half their waking hours with their teacher and school personnel. Yet most educators have had little training about the needs of children with medical conditions in the classroom. (Olson, Seidler, Goodman, Gaelic, & Nordgren, 2004, p. 53)

With limited knowledge and resources to draw from, well intended teachers and administrators respond to acute health episodes with impromptu plans, inadvertently creating educational barriers, eliminating the possibility of an equitable educational experience for students with an illness.

While federal legislation guarantees children with disabilities a free and appropriate public education (Individuals with Disabilities Education Act of 2004), children with chronic illness do not immediately fit into any pre-established programs in schools (Thies, 1999). When funds are determined through "head counts" of eligible children, these children are often overlooked, thus not accounted for in programs and budgets. As a result, eligibility for services is based on the definition appropriated by the funder of the program. The category of "other health impairment," outlined in the

ARE WE LEAVING CHILDREN WITH CHRONIC ILLNESS BEHIND 69

Individuals with Disabilities Education Act of 2004 (IDEA), attempts to be inclusive of children with illness; however the definition of a health impairment is restrictive as it requires a child to be actively experiencing “. . . limited strength, vitality, or alertness due to chronic or acute health problems” and this lack of vigor must adversely affect the child’s educational performance. This definition is not comprehensive in that children who are chronically ill can experience multiple issues related to their illness that interfere with school that may or may not be rooted in vivacity. Stuber (1996) describes the manifestation of school difficulties encountered by chronically ill individuals as a result of associated risk factors including short and long-term cognitive effects, and social, emotional and behavioral challenges.

BEST PRACTICES

Addressing the educational vacancy described above should be dealt with in the context of best practice. The discovery and implementation of best practice is pervasively emphasized in professional environments. In education and medical settings, best practice is more than a focus; it is a requirement to ensure quality care for consumers. Related to education, the No Child Left Behind Act of 2001 (NCLB) seeks to establish standards for best practice with an emphasis on data-driven decision-making and methods proven effective through scientifically based research (U.S. Department of Education, 2004). The sentiments of former President George W. Bush, “*Too many of our neediest children are being left behind*” (as cited in U.S. Department of Education, 2004, p. 13), capture the intent of NCLB. Unfortunately, some of the neediest children continue to be left behind, unacknowledged in legislation. NCLB outlines practices for economically disadvantaged students, English language learners and students with disabilities. Despite well documented educational implications related to the sequelae of many chronic illnesses, NCLB fails to define practices to address the specific needs of these children.

As Thies (1999) emphasizes, educators can anticipate the needs of chronically ill students thus preventing problems and optimizing academic performance just as they do for students with disabilities. Available research such as Kadan-Lottick et al. (2010), Suris, Michaud, and Viner (2004), and Mitby et al. (2003) provides evidence of cognitive sequelae for multiple chronic conditions. Diette et al. (2000) illuminate the problems associated with poor attendance for chronically ill individuals, and Adler et al. (2008) highlight the transitional issues for young adults with chronic illness related to lack of success in college and adulthood. The aforementioned research, in addition to other available resources, creates a sound platform from which best practices

70 PHYSICAL DISABILITIES: EDUCATION AND RELATED SERVICES

for the education of chronically ill patients can emerge. Consequently, categorizing children with chronic illness under the general blanket of students with disabilities is no longer acceptable.

Although best practices are not defined for the chronically ill, well-established practices in the field of education that all students benefit from are frequently overlooked as teachers and school districts work with children who are ill. Albeit unacceptable, the justification for holding proven practices tends to emerge in the absence of clear guidelines, lacking resources, and empathetic teachers fearful of maintaining high expectations for sick children. Educators' misperceptions and negative perceptions related to various chronic illnesses may also be the impetuses for inferior educational practices for these students. Olson et al. (2004) point out various trouble some findings, including attitudes of school personnel toward educating children with epilepsy that have remained unchanged since the 1970's (Holdsworth & Whitmore, 1974) despite medical advancements and new knowledge regarding education for these students. These authors further reiterate that negative personal biases of educators have resulted in lower academic expectations for children with AIDS and epilepsy.

Regardless of rationale, creating barriers and denying access to best practice for the chronically ill is unethical. An equivalent epidemic in a medical environment would be categorized as malpractice. While the type of care differs among these settings, the guiding principles of caring for such a vulnerable population should be the same. After all, many of these children come face to face with their own mortality, repeatedly choose to fight for their lives, and find ways to live with the various discomforts related to their illness. In response to their passion for survival, allowing the chronically ill equal access to well-established best practices in addition to crafting prescriptive guidelines seems the least educators can do in their role as caretakers of education.

VIOLATIONS OF BEST PRACTICE

Looking through the lens of chronically ill students, violations of best practice in education are plentiful. Although these violations are numerous, the atrocity of these offenses is not documented in the literature. Our direct experiences as professionals who support the educational journeys of patients and their families provide overwhelming anecdotal evidence of the devastating circumstances surrounding these common violations. Generally, most of the violations fall under the umbrella of two broad categories: free and appropriate public education (FAPE) entitlements and highly qualified teacher (HQT) regulations; within these are numerous offenses.

ARE WE LEAVING CHILDREN WITH CHRONIC ILLNESS BEHIND 71

Federal legislation guarantees all children a free and appropriate public education. According to Section 504 of the Rehabilitation Act of 1973, any school-age child with a disability, regardless of the nature or severity of the child's disability, is entitled to a free and appropriate education (U.S. Department of Education, 2007). This legislation defines a disability as any physical or mental impairment that substantially limits one or more major life activities, and an appropriate education refers to one that ensures equal access to educational services for all.

Withdrawal. In the face of Adequately Yearly Progress (AYP), a statute of NCLB, many children with chronic illness are viewed as attendance anchors. Attendance is one of the indicators measured for AYP and the fear of not achieving the required 92% drives many school districts to withdraw ill students from school when they have medical appointments or leave school for treatment. Unfortunately, we witness this as a common practice which has negative implications for these students during periods of treatment and recovery regardless of the duration of the absence.

If an appropriate education as defined by Section 504 mandates that the quality of education provided be equal, is the practice of withdrawing children with chronic illness from school appropriate? Under Section 504, a chronic illness can be categorized as a disability, consequently providing individuals with chronic illness protection from discrimination. Yet many children suffering from a chronic illness are being withdrawn from school due to their inability to attend school on a regular basis. School districts do not withdraw students with learning disabilities as a result of their disabling condition; therefore it should be unacceptable to withdraw children suffering from an illness.

In our experience as liaisons between the medical and educational communities, we routinely encounter schools who withdraw students due to effects of their illness. Some states do not prevent districts from temporarily withdrawing children when these students attend appointments at medical facilities located outside of the school district's domain; shockingly, this routine practice is employed for overnight and same day appointments. The act of withdrawing students is frequently facilitated without parental notification as districts complete withdrawal and readmission paperwork on behalf of the parents of ill students. In situations where parents are notified of the exercise of withdrawal, parents are left with no choice but to agree to the withdrawal as the only alternative is to be faced with truancy charges.

Children who are withdrawn from school feel exiled from the school community and the school is released from the responsibility of educating the child

72 PHYSICAL DISABILITIES: EDUCATION AND RELATED SERVICES

with an illness. Frequently, parents express frustration with the rigidity of school policies related to withdrawal and truancy and sometimes choose alternative educational paths to avoid the dreaded scrutiny encountered by school officials. Parents of children with juvenile primary fibromyalgia syndrome, for example, “typically cite the child’s pain or fatigue as the reason that they are unable to handle regular school hours. They also mention conflicts with school authorities about appropriate accommodations for the child’s disability as a reason for home schooling” (Kashikar-Zuck et al., 2010, p. 996).

The irony in this message is that although the school community detaches from the child, it is the yearning for attachment to school and community that provides youngsters with the tenacity to fight their illness. Childhood cancer survivors expressed the importance of education in the midst of treatment in Bessell’s 2001 study, which examined quality of life and school experiences of survivors. The overall sentiment of survivors related to education was captured in one participant’s feeling: “[I was] worth educating because survival was in the picture” (p.354). Although educating children who are chronically ill in light of frequent and/or intermittent absences can be challenging, maintaining enrollment demonstrates an acknowledgement of the school’s obligation to educate the child regardless of these challenges. Creative solutions can be sought to overcome a typical scheduling, resulting in mutually beneficial outcomes.

Regrettably, patients’ motivation to remain committed to school may taper as the children become aware of the “burden” they and their illness become to the school. In our work with the hematology and oncology pediatric population, we frequently witness this affliction manifest into fear as children become ashamed of their illness and petrified that their peers and teachers will be disappointed that they cannot keep up with age appropriate lessons due to instruction missed while withdrawn. Findings reveal that teachers were concerned not about “the academic issues or the impact on peers but the extra burdens and feeling personally at risk or uncomfortable having a child with a chronic health condition in their classrooms” (Olson et al., 2004, p. 56). The perceptive child, aware of this dynamic, must assume the weight of this perceived liability compounded with trepidation surrounding retention, future withdrawal, and feelings of inadequacy. How can a child who is fighting for life or struggling with chronic symptoms be expected to remain motivated and committed when the school district has dismissed him?

Retention. The threat of retention is frequently presented to parents and their children at their most vulnerable state – soon after diagnosis and in the midst of treatment. Best practice is again violated as educators of sick children

ARE WE LEAVING CHILDREN WITH CHRONIC ILLNESS BEHIND 73

ignore the evidence that suggests retention is contra indicated. This practice fails to demonstrate effectiveness in improving academic outcomes, and there are lasting consequences for those retained. Furthermore, grade retention can be detrimental for socio-emotional and behavioral outcomes, negatively impacting students' attendance, behavior, and attitudes toward school (Jimerson et al., 2006). Students perceive retention as a highly stressful life event, and retention is a strong indicator for dropping out of school.

Evidence indicates that poor health is a predictor for decreased educational attainment (Haas & Fosse, 2008). Students with chronic illness are already at a higher risk for drop-out than their healthy peers (Orr, Weller, Satterwhite, & Pless, 1984), have higher rates of absenteeism, are overwhelmed with socio-emotional issues, and experience highly stressful life events on a regular basis due to their illness. Unnecessary recommendations for retention which only increase the probability of these outcomes are inappropriate and highly contradictory to best practice. Because of poor retention rates in the United States, Jimerson et al. (2006) contend, "It is paradoxical that more children have been 'left behind' since NCLB was passed than before" (p.86). Retaining a child with chronic illness from advancing to the next grade level is evidence of these children literally being left behind.

Extended School Year. Extended school year (ESY) recommendations are similarly limiting for children with chronic illness. ESY opportunities may remedy lost instructional time through the school year due to illness-related absences, and may improve outcomes for children who experience cognitive impairments as a result of their disease and/or treatment by providing extended academic engagement. ESY qualifications vary between states; however access to ESY is frequently limited for children who are seriously ill. In our experience, many states reserve ESY services for students who exhibit significant regression compared to peers after breaks from school (i.e., holiday or summer break) before districts will consider providing ESY services. The danger in this approach is that access requires failure, as qualification is only considered after parents and educators can prove that the student has regressed over multiple time points. This discrepancy model too closely emulates the outdated "wait and see" method discarded from special education eligibility determination years ago. To "wait and see" is a violation of best practice for a population whose educational challenges are well documented in the literature.

Home Instruction. Typical home bound instruction conventions routinely violate educational best practices within the domains of FAPE and the highly qualified teacher (HQT) regulations. States and school districts

74 PHYSICAL DISABILITIES: EDUCATION AND RELATED SERVICES

employ arbitrary formulas to determine the amount of instruction children may receive based on time absent from the classroom. Most home instruction is generally limited to approximately one hour per day (and in some cases, less), and often home instruction will not go into effect until an extended absence has exceeded 15 days (Shaw & McCabe, 2008). Prolonged absences often required by medical needs are not remedied by the limited home instruction that districts are willing to provide (Sexson & Madan-Swain, 1995).

The limited instructional time provided through home instruction is clearly problematic, but the rarity of instruction being provided by a teacher meeting highly qualified status for content area subject matter in home instruction is less obvious – yet repudiates best practice as it relates to teacher certification. NCLB outlines teacher quality as a critical issue in guaranteeing all students access to the best teachers possible (U.S. Department of Education, 2004). However, the quality of instruction for seriously ill children requiring home instruction is frequently dependent upon teacher volunteers or a seniority system that rarely considers and habitually falls short of HQT standards. This is especially pertinent for children in secondary grades, when instructors charged with providing home instruction are not certified or experienced in teaching challenging and complex material beyond their own content area of expertise. The U.S. Department of Education cites research that correlates teacher quality with student academic achievement, though this correlation is frequently neglected in the selection process of home instructors. Home instruction is rarely discussed in the literature regarding education for children with chronic illness, and is also rarely addressed in legislation or policy (Shaw & McCabe, 2008). Once again, children with chronic illness are left behind without equal access to achievement by virtue of omission in the HQT standards and in the absence of guidelines for allotted hours afforded to students requiring home bound instruction.

Teacher knowledge. Even when these children return to the classroom, the educators' lack of familiarity with the educational implications of the child's disease challenges yet another aspect of FAPE. Most often, those charged with the responsibility of properly educating children with chronic illness are unaware of the complexity of academic issues that must be addressed in the classroom. Many children with chronic illness have lower achievement test scores than their healthy peers, even without evidence of cognitive impairments (Sexson & Madan-Swain, 1995). Moreover, evidence exists proving that many chronic illnesses actually do result in cognitive impairments. For example, children with AIDS may experience

ARE WE LEAVING CHILDREN WITH CHRONIC ILLNESS BEHIND 75

significant learning impairments (Papola, Alvarez, & Cohen, 1994), as can children undergoing specific treatment for, but not limited to, leukemia (Brown, Sawyer, Antoniou, Toogood, & Rice, 1999), brain tumor (Ris & Beebe, 2008), and pediatric renal transplantation (Davis, 1999).

Certain chronic illnesses such as diabetes and sickle cell disease are known to have long term neuropsychological effects, although these are the result of the disease process (hypoglycemia in diabetes and cerebrovascular accidents in sickle cell disease) rather than representing a generic chronic illness effect. (Suris et al., 2004, p. 939)

Yet "few educators perceived their students' [with a chronic illness] learning abilities as an issue" (Olson et al., 2004, p. 56).

Educators' lack of disease-related knowledge often results in missed opportunities for psychological referrals when evaluations and interventions may be needed. Teachers may attribute problems to the illness, thus allowing the impaired learning to continue without further intervention, and frustration and failure result from the student (Sexson & Madan-Swain, 1995). Behavioral and cognitive sequelae resulting from the illness may be overlooked or misunderstood by school personnel (Shiu, 2001).

More than half of the educators evaluated in the Olson et al. (2004) perceptions study reported a need for additional knowledge and training to better serve children with chronic illnesses. Opportunities for training are minimal, at best, despite this need. Few education programs include training for childhood chronic illnesses. Charging educators who lack the knowledge of the educational implications of the disease process with the responsibility of planning an appropriate educational journey for a child with a chronic illness is certainly not best practice.

SOLUTIONS

The educational system has been successful in creating laws to ensure safe environments and equitable opportunities for religious diversity (U.S. Const. amend. I, § 4071), for children with learning disabilities (Individuals with Disabilities Education Act of 2004), those with physical disabilities (U.S. Department of Education, 2007), and children with other needs. Similar provisions can be made for the chronically ill. Children with chronic illness have unique needs, but share in the need for equal access to educational opportunities (Shiu, 2001).

A proactive system should be established for serving the educational needs of children who are seriously ill. Research explains, in the case of

76 PHYSICAL DISABILITIES: EDUCATION AND RELATED SERVICES

many diagnoses, the educational implications for these children (Brown et al., 1999; Davis, 1999; Papola et al., 1994; Ris & Beebe, 2008; Suris et al., 2004), and in many cases, performance outcomes can be anticipated. Problems can be prevented or minimized with early interventions, thus waiting for problems to emerge before providing services is an outdated approach (Thies, 1999).

To maximize attendance and ensure educational growth, many of these children require coordinated school interventions (Sexson & Madan-Swain, 1995). While in some cases a specific special education plan may be appropriate, some of the traditional special education placements are not always ideal for these children. Although the spirit of the law and the special education process is intended to ensure unique and specific services based on individual needs, in our experience, children who are chronically ill are placed in programmatic structures and taught through strategies designed for children without an illness. Rather than placing students into special education programs designed for children with learning disabilities and developmental disabilities, schools can think differently about children with chronic illness by designing programs for these children that integrate their health and educational needs (Thies, 1999).

Olson et al. (2004) recommend the need for open discussions in both the medical and educational settings and improved training for teachers regarding the education of children who are chronically ill. Adler et al. (2008) echo the need for this partnership as they conclude more aggressive medical therapy coupled with better emotional support for individuals with inflammatory bowel disease (IBD) will likely result in improved college performance therefore providing long-term benefits for young adults with IBD; the results of this study are generalizable to other chronic illnesses.

Consideration of the educational needs of children with chronic illness must include more intentional planning, therefore resolving the current impromptu tendencies of school personnel. The examples of these improvised remedies are too numerous to list, however a few examples include enrolling students with an illness in alternative credit recovery programs designed for delinquent students or placing students in resource rooms to recoup lost instruction when this setting violates least restrictive environment guidelines. The creation of new mandates to address the unique needs of the chronically ill must be explored. With thoughtful effort, professionals can unite as catalysts to instigate the future direction of this field by collaborating on research endeavors. Results from these initiatives can subsequently guide policy and practice related to programmatic structures and specific teaching strategies for these children. Additionally, existing policies need to be expanded to ensure equal access to best practices for seriously ill

ARE WE LEAVING CHILDREN WITH CHRONIC ILLNESS BEHIND 77

children. Establishing clear guidelines will result in an equitable allocation of resources and funding resulting in more appropriate educational programming for these children.

CONCLUSION

Despite the best intentions of educators, policymakers, and legislative mandates, it seems as though children with chronic illness are being left behind in the educational system. Theis (1999) eloquently outlines the problems that remain for these children in the world of education:

Who is responsible for managing the education of an adolescent with [a chronic illness] who misses six weeks of algebra and biology – two to four days at a time? This question highlights the challenges to schools posed by children and adolescents with chronic illness. Unlike other disabilities, the course of illness presents a roller coaster of changing needs, moving between acute and medical crises and long term management of health. Children with chronic illness often fall between regular and special education, making do with accommodations until problems that could have been anticipated can no longer be ignored. Some move in and out of the special education system depending on their health status, a system whose policies, practices, and expectations are not necessarily a good fit. Special educators sometimes are not prepared to address the educational needs of children with medical illness. (p. 396)

Educational systems should facilitate educational attainment. Educational leaders, like physicians, should administer best practices, and teachers, like nurses, provide the direct services. The guiding principles that drive these systems should always be results from research. There is no question that it would be unethical to withhold best practices from patients, so why is it acceptable to withhold best practices in education from these students? Is it acceptable that chronically ill students are underserved due to nonspecific federal and state regulations and guidelines?

Analyzing existing research and laws to understand the path to success achieved for other vulnerable populations will likely guide future research initiatives that may lead to the solution so desperately needed for these children disadvantaged by the fate of their illness. Additionally, investigators need to take a closer look at the broad population of students with chronic illnesses to determine the similarities and differences associated with variables including types of illness, specific treatments, duration and severity of symptoms among other conditional factors that may help shape the educational interventions

78 PHYSICAL DISABILITIES: EDUCATION AND RELATED SERVICES

for this group of students. Fortunately, with deliberate effort, the solutions are well within reach.

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ARE WE LEAVING CHILDREN WITH CHRONIC ILLNESS BEHIND 79

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80 PHYSICAL DISABILITIES: EDUCATION AND RELATED SERVICES

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